

**INVOLVEMENT OF PERSONS WITH HIV/AIDS
IN TITLE I AND TITLE II PROGRAMS**

TECHNICAL ASSISTANCE CONFERENCE CALL

HELD DECEMBER 14, 1994

Arranged by:

Division of HIV Services
Bureau of Health Resources Development
Health Resources and Services Administration
U.S. Department of Health and Human Services

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EXECUTIVE SUMMARY

This report summarizes information presented in "Involvement of Persons with HIV/AIDS in the Title I and Title II Programs," the third in a series of nationally broadcast technical assistance audio teleconference calls arranged by the Division of HIV Services (DHS), Health Resources and Services Administration (HRSA). It is important to note that this summary reflects both the content of presentations and comments from listeners during the call. The teleconference call occurred December 14, 1994, with 87 sites and over 700 people participating nationwide.

The purpose of the teleconference call was to discuss requirements for and success in involving persons living with HIV/AIDS (PLWAs) in Ryan White Comprehensive AIDS Resources Emergency (CARE) Act Title I and Title II programs. Discussion focused on topics covered in two specific documents:

1. DHS Policy #1: Participation of People with HIV Disease on Title I HIV Health Services Planning Councils; and
2. A report by Gary McDonald, *Participation of People with HIV/AIDS in the Title I Planning Councils*.

Titles I and II of the CARE Act support direct services for people living with HIV/AIDS and create a comprehensive, participatory planning process designed to ensure that local health care and social service programs are responsive to the needs of persons with HIV and AIDS. DHS experience indicates that eliciting and maintaining effective PLWA involvement is both one of the most critical requirements and one of the major challenges facing Title I and II planning bodies.

DHS Policy #1 states that a minimum of 25% of the voting members of planning councils should be HIV-positive. These members are also expected to reflect the demography and epidemiology of HIV in the area. The policy specifies Title I planning councils, but DHS expects a similar level of PLWA participation in Title II consortia.

A DHS study examined four Title I eligible metropolitan areas (EMAs) to identify experiences related to eliciting and sustaining PLWA participation in planning councils. The resulting report, *The Participation of People with HIV in HIV Health Services Planning Councils*, addresses factors that encourage or discourage the recruitment and sustained participation of PLWAs on planning councils, and ways to obtain input from and provide feedback to PLWAs who are not planning council members.

The teleconference provided an opportunity to share and discuss a number of issues and DHS initiatives related to ensuring full inclusion of PLWAs in CARE Act programs. It provided a forum for discussion of such issues as:

- The importance of orientation and training for PLWAs to enable them to participate fully and encouraging their effective involvement in planning councils and consortia;
- Approaches that can be used to attract and maintain strong PLWA involvement in planning councils and consortia;
- Financial support available to support PLWA involvement in planning bodies;
- Structural considerations in ensuring PLWA involvement, including the importance and roles of PLWA advisory groups or caucuses; and
- Common barriers and challenges to PLWA participation, from fear of disclosure of HIV status to transportation, child care, and expenses.

DHS is involved in a variety of activities designed to facilitate PLWA involvement in Title I and II activities, as are many states and EMAs; these experiences offer lessons useful to other CARE Act communities and entities.

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I. INTRODUCTION

A. PURPOSE AND SCOPE

This report summarizes information presented in "Involvement of Persons with HIV/AIDS in the Title I and Title II Programs," the third in a series of nationally broadcast technical assistance audio teleconference calls sponsored by the Division of HIV Services (DHS), Health Resources and Services Administration (HRSA) to address topics of critical concern to Title I and Title II grantees. It is important to note that this summary reflects both the content of presentations and comments from listeners during the call. The teleconference call occurred **December 14, 1994.**

The purpose of the teleconference call was to discuss requirements for and success in involving persons living with HIV/AIDS (PLWAs) in Ryan White Comprehensive AIDS Resources Emergency (CARE) Act Title I and Title II programs. Discussion covered several topics related to establishing and maintaining PLWA involvement in CARE Act planning bodies, and focused on two specific documents:

1. DHS Policy #1: Participation of People with HIV Disease on Title I HIV Health Services Planning Councils; and
2. A report by Gary McDonald, *Participation of People with HIV/AIDS in the Title I Planning Councils.*

The teleconference included panelists from DHS, the consultant who prepared the report, and four Title I and II representatives, including three staff and one planning council member, of whom two were PLWAs. (See Appendix A for a list of panelists.)

B. PROCESS

Like the other teleconference calls in this series, the teleconference addressed topics and questions submitted by Title I and Title II grantees, consortium and planning council members, and CARE Act-funded providers. About 70 questions were received as part of the planning process and categorized for response. In addition, listeners had an opportunity to ask questions during the call. Over 700 people in 87 sites around the country participated in the teleconference call.

This report summarizes the content of the teleconference call by topic area and provides some updated information on the same topics. (See Appendix B for the teleconference call agenda.)

II. DHS ACTIVITIES AND POLICY

Titles I and II of the CARE Act support direct services for people living with HIV/AIDS and create a comprehensive, participatory planning process designed to ensure that local health care and social service programs are responsive to the needs of persons with HIV and AIDS. DHS experience indicates that eliciting and maintaining effective PLWA involvement is both one of the most critical requirements and one of the major challenges facing Title I and II planning bodies. DHS has carried out a variety of activities designed to understand and encourage strong PLWA involvement in planning councils and consortia, including the following:

- **A study** designed to identify key factors that contribute to initial and sustained participation of PLWAs as members of Title I planning councils, and creative methods for obtaining client feedback where full participation on planning councils was not possible. The resulting report is entitled *The Participation of Persons with HIV in Title I Health Services Planning Councils*.
- **Convening of constituency discussion groups** of PLWAs and other CARE Act constituencies, which led to recommendations related to DHS policy development and CARE Act reauthorization.
- **Convening of a another PLWA constituency group** which discussed and helped refine DHS policy regarding participation of PLWAs on planning councils, and also raised issues related to communication with the PLWA community and support of PLWA advisory groups.
- **Development of a policy** on Participation of People with HIV on Title I Planning Councils (See Appendix C for a copy of Policy #1).
- **Distribution of the policy** to both Title I and Title II grantees, with a request that they provide it and the report of the study listed above to all organizations and individuals who might benefit from receiving this information. With this package went an evaluation form asking for feedback on the policy, the report, and the idea of establishing consumer contacts in local communities.
- **Distribution of a survey**, which went with a second letter to Title I and II grantees providing an update on DHS activities. The survey sought information related to committees or caucuses of PLWAs that are officially linked with or involved in Title I and II processes and programs.
- **Establishment of an internal DHS Persons Living with HIV Disease Response Committee** which is seeking input from various sources and making recommendations to the Division on issues related to PLWAs.

DHS Policy #1 states clear expectations for representation of HIV-positive persons among planning council membership. It states that:

The CEO, EMA grantees, and Planning Councils must ensure that there is adequate representation of HIV-positive and affected (partners, spouses, parents, siblings) individuals as voting members of the Council. Councils will implement a requirement that a minimum of 25 percent of their voting members must be HIV-positive. These members must reflect the demography and epidemiology of HIV in the EMA (as should the full membership of the Planning Council).

While the policy specifies Title I planning councils, DHS believes that Title II consortia should work to ensure the same level of PLWA participation.

DHS is seeking ways to encourage increased interaction between community-based PLWA organizations and CARE Act planning bodies. In addition to communicating with contact people within the grantee structure, DHS is exploring the idea of seeking one or more additional contact people within the HIV community of each Title I and Title II grantee who can carry information from DHS to that community. DHS is also working with the National Association of Persons Living With AIDS and the computer network system as potential vehicles for communication with the PLWA community. Each grantee also has a responsibility to ensure that information from DHS is shared with others in the community who need it as input to decision making.

DHS is committed to having all planning councils reach the 25% minimum participation level for PLWAs. The PLWA participation policy states that:

In cases where Planning Councils have not yet reached a minimum of 25 percent HIV-positive membership, the Planning Council must develop and implement within six months of the effective date of this policy (or the start date of the formula budget period for the first year of Title I eligibility) a plan with related activities and timelines, acceptable to DHS, to achieve the requisite recruitment and sustained participation of people with HIV disease in Planning Council processes.

Some planning bodies are requiring that a fixed percentage of the membership of certain committees be PLWAs. There is no DHS policy specifying such percentages, but there is a trend towards fixed percentages of PLWA membership on various committees. In Philadelphia, for example, the Resource Allocation Advisory Committee is mandated to have 50% PLWA membership.

DHS is systematically incorporating into its materials the commitment to communicate on three levels: with the grantee community, the planning bodies convened under Titles I and II, and the community, specifically PLWAs. Focused technical assistance is also

available to help grantees, planning councils, and consortia secure or improve PLWA participation at the local level.

III. TRAINING FOR PLWAs

Training for PLWAs is an essential component of a strategy for full inclusion of PLWAs in Title I and Title II programs. Training should cover two types of needs:

- **Issues of self-worth and internalized oppression that affect many persons infected with HIV.** PLWAs are unlikely to feel emotionally comfortable as partners in the planning process, able to question authority figures and maintain effective peer relations, until they have dealt with these issues.
- **The technical knowledge needs of HIV-infected planning council and consortium members,** such as an understanding of the CARE Act legislation and implementation process, the EMA or consortium area's service delivery system and provider profiles, needs assessment and allocation procedures, as well as how things get accomplished and how quickly change occurs.

Training should also take into account the problem of burnout. As PLWAs become aware of their potential as community leaders, they may start to take on too much work. Training needs to help individuals make realistic time commitments and avoid becoming overcommitted.

Training location is important. Some of the same barriers exist for training as for attending meetings: transportation, child care, and expenses. Ideally, training should occur at the local level; sessions should be provided at several different sites, especially if the Title II consortium or Title I EMA covers a large geographic region, to maximize participation.

A guide for training PLWAs is now being developed. Grantees, planning councils, and consortia are welcome to provide input to the guide and should feel free to contact Project Officers for help with their training efforts.

IV. ORGANIZING AND SUPPORT

DHS commissioned a study to examine organizing and support related to eliciting and sustaining PLWA participation in planning councils. The study involved in-depth interviews and focus group discussions with a total of 113 persons, 90 of them HIV-positive, in four Title I EMAs: Atlanta, Philadelphia, San Diego, and Seattle. The resulting report, *The Participation of People with HIV in HIV Health Services Planning Councils*, addresses factors that encourage or discourage the recruitment and sustained participation of PLWAs on planning councils, and ways to obtain input from and provide feedback to PLWAs who are not planning council members. The study provides insight into a number of questions and issues related to PLWA involvement in CARE Act programs. Many of the findings may well apply to Title II consortia as well as other Title I planning councils. Some important findings are summarized below by topic.

Affected vs. infected communities: The four planning councils studied make a distinction between affected and infected communities. As one person put it, "everybody is affected by HIV," so it is important to concentrate on those infected with HIV. Of the four planning councils studied, three interpret the legislative language to mean they should appoint HIV-positive members; the other -- San Diego -- specifically reserves two seats on its planning council for family members or care givers of PLWAs.

Recruiting PLWAs: The planning councils studied use personal contacts and individual interactions as the chief means of recruitment; this seems to be the case in other EMAs as well. Recruitment generally requires personal contacts with potential members, but outreach beyond individual networks is important in widening the search. Some councils have created nominations and membership committees as a way of overcoming problems encountered in recruiting diverse people. Methods of outreach used by the four councils include advertisements in local publications, among them publications for HIV-positive people, and public meetings arranged by contacting service providers. One council has an open membership policy which permits PLWAs to become voting members after they attend three consecutive meetings.

Recruiting a diverse group of PLWAs: In all four planning councils, there has been an evolution in PLWA recruitment which seems to be typical of CARE Act planning bodies. The groups began primarily with "convenience" members, primarily white gay men who were already involved in the process. Over time, as the demography of HIV changed, and the membership of the planning councils did not reflect these changes, there was agitation for greater diversity. All four planning councils added HIV-positive people reflecting greater numerical representation and diversity. Attaining diversity among PLWA representation requires carefully planned outreach into many different communities, with the help of a variety of individuals and community groups.

Sustaining PLWA involvement: The planning councils studied did little or nothing to support PLWA participation over time. All perceived this to be a problem, and several were

seeking ways to address it. PLWAs made specific recommendations for support, including the following:

- **Shorter and more convenient meetings;** it is difficult for PLWAs to travel long distances to meetings but this is often required when the planning council covers a geographically large area (and is even more likely for Title II consortia).
- **Reimbursement of expenses, particularly meals;** some planning councils offer meals during meetings.
- **Orientation** when they first join the planning council, covering not only background on the council structure and processes, but also such topics as how to read and analyze documents like budgets and spreadsheets.
- **Mentoring,** through which an experienced current member, not necessarily HIV-positive, works with the new PLWA member for the first three to six months, providing background information, answering questions, helping the new member to understand planning council meeting processes, and otherwise sharing knowledge and experience.
- **A proxy or alternate member mechanism,** in case the member becomes ill.
- **Guidance on appropriate levels of involvement,** such as how many committees the new member should join.

Some of these recommendations have been incorporated into the DHS policy on PLWA participation, which states that:

Consumer membership should be supported through formal orientation and training processes followed by ongoing mentoring from other members. In addition, Councils should establish alternate appointments for HIV-positive members, provisions for absentee or proxy votes, other means to accommodate HIV-positive member absences due to health or related issues, and additional membership slots for HIV-affected individuals.

Other methods of involving PLWAs: Because of significant barriers to sustained membership on planning councils, most HIV-positive people will not join planning bodies. Other methods of obtaining meaningful PLWA participation need to be developed. All the planning councils studied felt that they had to become more proactive in developing recruitment and feedback mechanisms. Some approaches such as public meetings were not considered very effective. The following approaches were recommended:

- Open voting membership on key committees to non-planning council members.

- Enable a PLWA to become a voting member of a committee after attending three consecutive meetings, even if s/he is not a member of the planning council itself.
- Advertise and hold public meetings specifically to obtain input from PLWAs.
- Conduct surveys, including mail-in cards.
- Carry out focus group discussions.
- Do exit interviews with clients where they receive services.
- Provide consumer evaluations of service providers.
- Conduct surveys to identify unmet client needs.

Reaching PLWAs who are outside the system: Some PLWAs are outside the system of care, and therefore are not a part of the needs assessment process and are not receiving badly needed services. Special outreach efforts, usually involving one-on-one personal contact, are needed to find and involve them. Assigning a peer figure to do outreach work and cultivate contacts within the community is helpful; community organizers with groups such as community development corporations can be valuable resources. Another approach is to look to clients who are now receiving services but are somewhat similar to the hard-to-reach population, and have contacts within a particular client community. In Massachusetts, someone stayed in homeless shelters for a couple of months to identify people in need of services; this level of commitment made people willing to disclose their status and accept treatment.

Mr. Kiyoshi Kuromiya, a PLWA who is the founder of the PLWA organization Critical Path and a member of the Philadelphia planning council who participated in the study, provided a personal perspective (His full remarks are included as Appendix D of this report). He noted that:

For the first time in history, a community of patients and their advocates have been given a voice in the federal processes that determine what services are appropriate and needed. It is vital for us all that persons with AIDS get involved locally and nationally in this process, otherwise our seats at the table will disappear from lack of participation.

He described health care as "the new civil rights battleground, and noted the "doubly difficult" task of PLWA treatment activists:

- "Bringing community issues to the table"; and

- "Bringing treatment, research, and care issues to our communities" at a time when the priorities of disenfranchised communities often involve issues other than AIDS.

He explained the deeply rooted mistrust of the federal bureaucracy and the political process among communities of color, but also emphasized the importance of working with the treatment, research, and care establishments to get "experimental drugs and vital services" to the communities that need them most. He also noted that while becoming involved in the process might be seen under other circumstances as "time-consuming and even onerous," it can also lead to results, such as voting representation on Title I and II planning bodies and standing committees. He stressed the need for continued participation and vigilance. Past efforts provide a foundation for future efforts:

Our ranks are now very much depleted by death and burnout, and we need to stress the importance of participation by a new generation, even more diverse than the last, of patient activists and advocates. This life and death struggle is only empowering if you are a part of it.

V. FINANCIAL SUPPORT

Financial support for PLWA involvement needs to be addressed with respect to several different categories of issues:

- What kinds of CARE Act funds are available for use in providing financial support for activities related to PLWA involvement;
- What kinds of expenses can be covered for PLWAs; and
- What constitutes "reasonable costs."

Sources of financial support: Two funding mechanisms are available. Under Title I or Title II grants, funds are available not only for administrative costs but also for planning body support. Funds from planning council or consortium support budgets can be used to support the participation of PLWAs. In addition, DHS technical assistance resources can be used either to meet individual grantee needs or to support an activity involving or benefiting multiple grantees or planning groups and PLWA groups. For example, a training manual focusing on training for PLWAs is being developed using technical assistance funds.

Types of expenses: CARE Act funds can be used to cover expenses for PLWAs such as child care, transportation, or other meeting-related costs. In addition, contracted services can be used, such as transportation or child care services. Grantees or planning bodies are also permitted to provide budget support for PLWA participation in conferences. Stipends or honoraria are not permitted as cash payments using Ryan White funds, but expenses for activities related to planning council or consortium participation can be reimbursed. If alternate funds are available

for stipends, grantees may give PLWAs the option of receiving a stipend for services or not, since payment of stipends and honoraria may affect eligibility for Medicaid coverage or for Supplemental Security Income (SSI) or other entitlements which have income caps. Some grantees have found that it preferable to reimburse expenses instead of providing stipends for PLWA services; funds can be used to reduce the costs incurred, from transportation and meal costs to purchase of pens or other expenses. A stipend in the range of \$25 per meeting is unlikely to jeopardize a person's entitlement eligibility, but cannot be paid with Ryan White funds. An alternative could be to provide food gift certificates purchased at a supermarket.

Reasonable costs: There is interest in having a framework which helps grantees, planning councils, and consortia determine what costs are "reasonable." DHS is working on a policy which provides guidelines concerning what might constitute "reasonable" expenditures for non-administrative, non-direct service costs such as planning council or consortium support.

VI. ORGANIZATIONAL DEVELOPMENT

Once a planning council or consortium has committed itself to inclusion, it must determine what kinds of structures and processes will help involve PLWAs fully and effectively. This requires considering the configuration of both the planning council or consortium and other bodies such as subcommittees or caucuses. Of special concern are the roles of subcommittees, ad hoc groups, or advisory groups, including the extent to which the work and perspectives of such entities get communicated to the planning body.

Making an advisory or ad hoc committee effective requires careful planning. It is particularly important that the parent body provide the following:

- A clear mission statement and clear guidance from the planning body;
- Defined composition or membership;
- The expected number and frequency of meetings;
- Clear lines of authority, specifying to whom the committee reports; and
- Clear responsibility for using and responding to committee actions or recommendations.

Advisory groups need guidance to understand what constitutes a reasonable response to their work. They need to recognize that the planning council or consortium cannot always incorporate all the group's recommendations. On the other hand, if the group had something valid, reasonable, and logical to say, it should be able to expect a clear and substantive

response. The group should document ideas, opinions, and/or recommendations in written form and request a written response. If something the group has recommended cannot be done, members should be told why this cannot be done, and such responses should be provided in writing.

An important question for PLWAs is how to hold the "powers that be" accountable. Familiarity with the CARE Act system and procedures helps PLWAs influence the process and decisions. Orientation for PLWAs should include a clear "map" of the system and how it works. This includes an understanding of structure -- what committees exist, what are their mandates, when do they meet, who are the leaders and what are their telephone numbers, etc. This kind of information helps provide access to the people who are a part of the system.

PLWA advisory groups or caucuses need models for working effectively with the consortium or planning council yet at the same time continuing to represent and serve the HIV community. A group committed to reaching out to the HIV community and getting other HIV-positive people involved in the planning body might operate under either of two models:

- **The group might function as a part of the Ryan White CARE Act system.** It might be a planning council- or consortium-affiliated caucus or advisory group composed 100% of consumers, which nominates PLWAs to serve as members of the planning body and also provides direct consumer input to that body. Under the planning council or consortium structure, it could be delegated responsibility for nominating PLWAs for membership in the planning body, thus identifying the 25% of members who should be HIV-positive according to DHS policy.
- **The group might operate outside the CARE Act system.** It might be an independent body which has an agreement with the planning council or consortium to nominate HIV-positive people to serve as members of the planning body. It might also provide other kinds of input to the planning body. At the same time, it could also engage in activities unrelated to the CARE Act.

In either model, the group could be composed entirely of people who are HIV-positive. It could consider and take a position on any topic of concern and put forward its ideas to the planning council or consortium or to other entities.

One of the major challenges to maintaining PLWA involvement in planning bodies and advisory groups is keeping people at the table when their ideas and recommendations cannot be implemented. Such limitations as a lack of staffing may be preventing PLWA recommendations from being carried out. PLWAs sometimes find it hard to understand and accept some of the constraints within service systems. Orientation and training for consumer

members can help them modify what may be unrealistic expectations for change and the rate of change, and recognize some of the complexities within the system.

PLWAs should follow the same rules regarding conflict of interest as other planning council and consortium members. Perception of conflict of interest can be as detrimental to the process as real conflict of interest. Appropriate committee configurations can often help avoid real or perceived conflict of interest. For example, instead of having a full planning body make funding recommendations, members might be divided into subgroups of providers and PLWAs to review proposals covering geographic areas other than their own.

Sometimes PLWAs who become active in planning councils and consortia are hired by or elected to the Boards of Directors of providers -- thus assuming provider status. Such individuals often have a great deal of valuable experience, which the planning body can ill afford to lose. However, their involvement must now be as a provider representative. The employment of such individuals by providers should be viewed as a positive side benefit of their CARE Act involvement; it may mean that they do not have to retire or depend on SSI and can play a valuable role while being paid for it. Ongoing outreach, organizing, and training are important to generate a pool of PLWAs, so that members of the planning council or consortium who become employed can be replaced by other well-prepared PLWAs.

Similar role changes can occur with organizations. In one community, a PLWA committee which had been serving a consumer advocacy role became a subcontractor to the lead agency in a Title II consortium. The new role compromised its whole mission; a PLWA group cannot at the same time accept funds from the consortium and be responsible for nominating its PLWA members.

VII. BARRIERS AND CHALLENGES

Many barriers discourage sustained PLWA involvement in planning councils and consortia. Some of the most frequently mentioned are listed in the box.

Rural areas and Title I or Title II areas which cover large physical distances present special challenges for PLWA participation. In parts of Arkansas, for example, there is no rapid transit system and taxicabs are few and expensive, so volunteers bring PLWAs to meetings. Sometimes expenses are reimbursed. In Arkansas, involving PLWAs is done on a one-to-one basis, and a network has been formed.

Burnout can be a serious problem. Often, new planning council or consortium members try to do too much too quickly. Particularly in rural areas, where it can be very difficult to involve PLWAs, action is needed to keep the PLWAs who are participating from getting discouraged and tired. One successful approach in Vermont has been to develop small work groups so that people can have an active voice in the process without making long-term commitments to large organizations. The groups can be geographically based to reduce travel time, and minutes and other information about the work of a particular group are shared with people in other areas. Consumers are also asked to provide feedback and input regarding how the process could be improved or how services could be strengthened.

Disclosure of HIV status is a difficult issue. Particularly in rural areas, grantees report difficulties in finding people willing to self-identify as HIV-positive. People may want to participate in the process but remain anonymous. A number of approaches have been used to address this issue. For example:

- In one rural area, PLWA representatives on the statewide consortium communicate with the PLWA community, obtaining input from individuals who may not be comfortable publicly disclosing their status.
- Small ad hoc groups can provide individuals a forum for offering input without having to disclose their status.

BARRIERS TO SUSTAINED PLWA PARTICIPATION IN CARE ACT PLANNING BODIES

- Large geographic areas and long distances to travel to meetings
- Bad weather
- Transportation problems including cost
- Disclosure of HIV status
- Financial costs
- Burnout

- Holding meetings which are not identified as PLWA meetings in facilities which are visited by a multitude of people can also reduce concerns about disclosure.
- Some rural areas with transportation and disclosure concerns hold periodic conference calls to obtain community input; people need not self-identify as HIV-positive and are not required to give their names.
- One way to address the problem of disclosure is to reframe the language to publicly identify people as "consumer advocates" or "community health advisors" rather than PLWAs. While being described in this way requires disclosure to the planning body, the term does not immediately identify an individual as HIV-positive to people unfamiliar with CARE Act programs.
- Case managers can often identify people with an interest in CARE Act involvement, and discuss and allay their fears about self-disclosure.

Sometimes individuals become more willing to become involved and to disclose their status after participating in activities that motivate them. For example, Massachusetts has held one- or two-day consumer institutes for people who are active in planning or leaning towards becoming active. The sessions enable people to come together in a site outside their own rural area, where they are not afraid to disclose. Once they come together and form a critical mass, they usually become excited and involved. They meet other people who are doing similar work, learn from each other, and become motivated to get more involved themselves.

An important question is whether disclosure is required in order for an individual to be counted among the 25% of planning council members who are PLWAs. DHS will rely on the grantee to be honest and will not ask for name disclosure. However, it would be very difficult for someone to represent the HIV-positive community without being identified as such to the planning body. Many PLWAs feel very strongly that a person who is not self-identified cannot be a speaker or voice for that group.

VIII. CONCLUSIONS

The teleconference provided an opportunity to share and discuss a number of issues and DHS initiatives related to ensuring full inclusion of PLWAs in CARE Act programs.

The call highlighted the DHS policy on PLWA participation on Title I planning councils; the expectation exists for 25% PLWAs among the voting membership of consortia. The teleconference also reported on the results of a study of four planning councils which identified factors for creating and sustaining PLWA involvement in Title I programs. It provided a forum for discussion of such issues as the following:

- The importance of orientation and training for PLWAs as a means of enabling them to participate fully and encouraging their effective involvement in planning councils and consortia;
- Approaches that can be used to attain and maintain strong PLWA involvement in planning councils and consortia;
- Financial support that can be provided to support PLWA involvement in planning bodies;
- Structural considerations in ensuring PLWA involvement, including the importance and roles of PLWA advisory groups or caucuses; and
- Common barriers and challenges to PLWA participation, from fear of disclosing HIV status to transportation, child care, and expenses.

DHS is involved in a variety of activities designed to facilitate PLWA involvement in Title I and II activities, as are many states and EMAs. The teleconference helped increase awareness of these activities and the lessons they offer for other communities and entities working to create and maintain full and effective PLWA involvement in Title I and Title II programs.

APPENDIX A PANELISTS

MODERATOR

Andrew Kruzich, Project Officer, Western Services Branch, Division of HIV Services

PANELISTS

Steven Young, Chief, Eastern Services Branch, Division of HIV Services; former Deputy Chief of the Training and Technical Assistance Branch, where he helped develop DHS Policy #1 on Participation of People with HIV Disease on Title I HIV Health Services Planning Councils

Gary McDonald, Consultant, Academy for Educational Development AIDS Communication Support Project and author of "The Participation of Persons with HIV in Title I Health Services Planning Councils"

Bill Lottero, Director, Consumer Advisory Board System, HIV/AIDS Bureau, Massachusetts Department of Public Health

Eda Valero-Figueira, Project Officer, Eastern Services Branch, Division of HIV Services

Kiyoshi Kuromiya, member, Philadelphia Title I Planning Council and founder, Critical Path

Michael Gilman, Program Coordinator, AIDS Program, Vermont Department of Public Health

Steven Land, Northern Arkansas Regional AIDS Network

APPENDIX B

AGENDA

- I. Overview
- II. Review of DHS Activities Relative to PLWA Involvement and DHS Policy
- III. Training
- IV. Organizing and Support Related to Eliciting and Sustaining the Participation of PLWAs
- V. Audience Questions and Answers
- VI. Financial Support
- VII. Organizational Development
- VIII. Audience Questions and Answers
- IX. Barriers and Challenges - Transportation, Rural, Other
- X. Audience Questions and Answers
- XI. Wrap-Up

APPENDIX C

POLICY #1: PARTICIPATION OF PEOPLE WITH HIV DISEASE ON TITLE I HIV HEALTH SERVICES PLANNING COUNCILS

**BUREAU OF HEALTH RESOURCES DEVELOPMENT
DIVISION OF HIV SERVICES
Policy # 1
Participation of People with HIV Disease
on Title I HIV Health Services Planning Councils**

I. Background

A central tenet of the Ryan White CARE Act is provision of Federal authority and funding which supports local decision making based on need. A requisite element of all Ryan White programs, but especially those funded under Title I, is effective planning and decision-making based on the documented needs of those with AIDS and HIV disease. This is optimally attained through a comprehensive, participatory planning process that involves those who need and utilize the services offered locally.

In providing for a Planning Council under Title I, a Chief Elected Official (CEO) is responsible for establishing the Council directly or designating an existing entity with demonstrated experience in planning and implementing plans for HIV health care services within the eligible metropolitan area (EMA) to serve as the Council [Sec. 2602(b)(2)(A and B)]. The legislation specifically requires that Title I HIV Health Services Planning Councils include membership from affected communities, including individuals with HIV disease [Sec. 2602(b)(1)(G)].

The experience of DHS in administering this program since FY 1991 confirms the importance of this involvement in ensuring that local health care and social service programs are truly responsive to the needs of those with AIDS and HIV disease. However, this initial experience also indicates that eliciting, maintaining and maximizing the value of this involvement is a significant challenge for many Planning Councils.

In response to these challenges, the Division of HIV Services presents the following policy statement to be implemented by all Title I grantees and HIV Health Services Planning Councils.

II. Policy Statement

The CEO, EMA grantees and Planning Councils must ensure that there is adequate representation of HIV-positive and affected (partners, spouses, parents, siblings) individuals as voting members of the Council. **Councils will implement a requirement that a minimum of 25 percent of their voting members must be HIV-positive.** These members must reflect the demography and epidemiology of HIV in the EMA (as should

the full membership of the Planning Council). Consumer membership should be supported through formal orientation and training processes followed by ongoing mentoring from other members. In addition, Councils should establish alternate appointments for HIV-positive members, provisions for absentee or proxy votes, other means to accommodate HIV-positive member absences due to health or related issues, and additional membership slots for HIV-affected individuals. In cases where Planning Councils have not yet reached a minimum of 25 percent HIV-positive membership, the Planning Council must develop and implement within six months of the effective date of this policy (or the start date of the formula budget period for the first year of Title I eligibility) a plan with related activities and timelines, acceptable to DHS, to achieve the requisite recruitment and sustained participation of people with HIV disease in Planning Council processes.

III. Suggestions for Policy Implementation and Attaining Compliance

1. Planning Councils should designate a Nominating or Membership Committee with responsibilities which include publicizing the need for and recruiting HIV-positive members. This activity should be carried out via proactive outreach to service providers, support groups and advocacy organizations through existing communications channels such as newsletters, community liaisons and as part of community survey mechanisms. In soliciting new HIV-positive members, Councils should clearly delineate the time and other commitments required of members and describe the support available to HIV-positive members to facilitate participation in Council activities. The Council's position should be stated clearly regarding disclosure of HIV status. Additionally, Council policies regarding affiliation (as a board member, employee, or contractor; anything other than a recipient of service/s) with any organization/s receiving funding from Title I of the Ryan White CARE Act must be clearly explained to all potential members, including those with HIV/AIDS.
2. Planning Councils should establish a formal program of support to facilitate the participation of HIV-positive members. This support may include flexibility in membership expectations regarding factors that are affected by health status (time, attendance, assignment to various activities), and reimbursement of incidental expenses related to transportation, parking, and child care incurred while attending meetings or on official business related to service on the Planning Council. All meetings should take place in handicapped accessible facilities and consideration should be given to rotating the location of meetings to accommodate the geographic size or diversity of the EMA and accessibility by people with AIDS and HIV throughout the region. Consideration should also be given to the day and time for meetings that best accommodates and maximizes participation of HIV-positive individuals.

APPENDIX D

REMARKS OF KIYOSHI KUROMIYA ON PARTICIPATION OF PEOPLE WITH AIDS IN RYAN WHITE TITLE I AND II COUNCILS

People With AIDS (PWA) Participation in
Ryan White Title I and II

Conference Call -- December 14, 1994

Remarks of Kiyoshi Kuromiya

For the first time in history, a community of patients and their advocates have been given a voice in the Federal processes that determine what services are appropriate and needed. It is vital for us all that persons with AIDS get involved locally and nationally in this process. otherwise our seats at the table will disappear from lack of participation.

Within communities of color and other marginalized groups. PWA treatment activists have a doubly difficult task to perform. Bringing community issues to the table and at the same time bringing treatment, research, and care issues to our communities -- not to mention issues of our own personal care and feeding which can be and often are ignored or given second priority. Often, in fact, usually, AIDS and treatment issues get short shrifted in disenfranchised communities since priority often tends to go to issues of substance abuse, housing, access to primary health care, discrimination (racism, homophobia, and sexism), and the overriding issues of poverty, marginalization, and powerlessness.

In historic perspective, we've got to understand that health care is the new civil rights battleground, and we must participate, otherwise we lose the battle for our communities. We must remember that the United States of America and the Union of South Africa bear the unhappy distinction of being the only developed countries on the planet which do not guarantee health care for their own citizens.

The mistrust of the Federal bureaucracy and the corporate structure in this country have historic roots in communities of color. In my own case, I should point out that I was born behind barbed wire and machine gun towers in Heart Mount, Wyoming. a windy and desolate 9000-foot-high plain in the Rockies. I was born there because 120,000 persons of Japanese ancestry were imprisoned for three years in concentration camps -- hastily constructed in isolated areas during World War II. We were stripped of all rights, not because of a crime. but because of race. Understandably, a mistrust of political process and Federal officials runs deep in our communities of color.

Yet, as a person living with AIDS, I have also found that we need to work with the treatment, research and care establishments because without that process, experimental drugs and vital services will never reach communities that need them the most; and instead we will be further victimized. It is important that we realize that we must participate in what, under other less urgent circumstances, is a time-consuming and even onerous process. It has its rewards; we marched into a Ryan White meeting several years ago demanding seats at the table. We got them, along with voting seats on all standing committees for Ryan White Title I and II. It is this experience of winning that is fulfilling, but as in any political process, we must continue our participation and vigilance, otherwise we will soon find that we can easily get manipulated, co-opted, or legislated out of the picture.

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The efforts that have been made in the early years of the epidemic by many persons, some of whom are no longer able to participate, provide us a good foundation for future efforts. Our ranks are now very much depleted by death and burnout. and we need to stress the importance of participation by a new generation, even more diverse than the last, of patient activists and advocates. This life and death struggle is only empowering if you are a part of it.